



*For people with intellectual  
and developmental disabilities*

**Testimony  
of  
Peter Berns, CEO  
The Arc of the United States  
on  
The American Health Care Act  
March 16, 2017 Hearing**

The Arc of the United States appreciates the opportunity to submit testimony today on the draft legislation that repeals the Affordable Care Act, or ACA, and pays for it by decimating Medicaid, a program critical to the lives of people with intellectual and developmental disabilities. The Arc is the largest national community-based organization advocating for people with intellectual and developmental disabilities, or I/DD, and their families, with over 650 state and local chapters nationwide.

I'm here today representing more than 65 years of history and countless people with disabilities, their families, friends, and professionals that support them. We have come a long way, from a society that warehoused people in institutions to one in which people with intellectual and developmental disabilities belong in the community and have fundamental moral, civil, and constitutional rights to be fully included and actively participate in all aspects of American life.

The American Health Care Act would turn back the clock on this progress. Let me give you some context. The vast majority - 77 percent - of the supports and services that individuals with I/DD use to live in the community are funded through the Medicaid program. These supports and services include help with meals, bathing and dressing, in-home skilled nursing, and communication, to name but a few. These supports and services are the linchpins to a life in the community, a life of meaning, and in many cases, they can be the difference between life and death.

Just this week, The Arc's staff talked to a mom from Maryland, whose eleven year old daughter has Rett syndrome. For years, she and her husband took turns staying up all night with their daughter, to keep her alive. Around the clock, their little girl requires suction and other care just to keep breathing. About a year ago, her pediatrician sat

them down to help them find a solution to this unsustainable situation, one that would keep them all healthy. Finally, the family was able to get the support they needed - for their little girl to get nighttime nursing care, and for her parents to get more than one night of sleep between them at a time. This is possible because of the Medicaid program. Stories like this family's are repeated many times in every community throughout our nation for children and adults with I/DD.

Unfortunately and frighteningly for these families and individuals, the new AHCA repeals critical parts of the ACA and replaces them with an approach to health care coverage that leaves millions behind.

The Medicaid expansion in the ACA has given access to healthcare to people with disabilities and their families, as well as to direct support professionals. The repeal of these provisions will destabilize the Medicaid program as states scramble without adequate federal support. The new bill would replace the ACA affordability provision with tax credits that are unlikely to be enough to maintain affordability for low and moderate income people. While many of the policy points are troubling, it is even more troubling and simply unconscionable to use the Medicaid program to pay for the repeal of the ACA, the repeal of corporate and provider taxes, and to provide new tax benefits for individuals included in the new bill.

The drastic approach of capping federal funds flowing to the states for the Medicaid program will have a devastating long-term impact. For over 50 years Medicaid has been a Federal/State partnership where the costs were shared between the states and the federal government. Under the cut and cap proposal, the federal government is turning its back on the states and leaving huge funding gaps for the states to fill.

We have real fears that optional Medicaid services like home and community based services are at great risk, despite longstanding bipartisan support of these programs. Home and community based services are vulnerable because, when facing losing billions, states will have to continue providing mandatory services such as institutional care and nursing home beds instead of the preferred and more cost effective HCBS. The current per capita cap proposal that would pay for the repealed components of the ACA would force states to come up with an \$880 billion difference over a decade. The Congressional Budget Office anticipated that, in response to changes made by the bill, states could "cut payments to health care providers and health plans, eliminate optional services, restrict eligibility for enrollment, or (to the extent feasible) change the way services are delivered to save costs."

Medicaid is already a lean program, states have already had to cut human services budgets. How can a state make up the difference in funding? We fear it will be from these optional services - and people with I/DD will have the real fear that they will end up back in institutions.

The catastrophic result could be a shrinking community for people with disabilities. There will be limited availability of home and community based services, scaled back

eligibility for services, reduced reimbursement rates for these services, and growing waiting lists. These cuts will pave a path backwards into overreliance on institutional care and segregated services.

We have heard from thousands in our network on the truly devastating impact that these proposals would have on their lives and the lives of their loved ones. I'm thinking of one board member and his wife from The Arc of North Carolina. When staff of The Arc of NC explained what was happening here in Washington, what was at risk for Medicaid, I have been told that his comment brought the room to tears. He said "I'm old, and I'm going to die in the next five years. My life's work has been to keep my son in the community in a meaningful way. To give him a life. Do you mean to tell me that I'm gonna die, he's going to end up in an institution all alone, and what we built is for nothing?"

We cannot let our answer to this man be yes - we cannot let his son's future fall apart, and we cannot turn our back on the commitments we have made as a society to people with intellectual and developmental disabilities and their families.

We are pleased that Rep. Hoyer wanted to spotlight the concerns of the disability community in this forum. We think it is critical because the devastating impact of the per capita cap proposals have not received enough national attention. We know that these proposed Medicaid cuts will be life altering to children and adults with disabilities.

This approach is morally reprehensible, and our nation cannot let this happen.